# Comprehensive Cancer Control and Survivorship

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### Comprehensive Cancer Control

is an integrated and coordinated public health approach that fosters partnerships to reduce cancer incidence, morbidity and mortality through the implementation of evidence-based services, systems, policies and research related to a continuum of cancer-related activities, from prevention through early detection and treatment to rehabilitation and palliation.



# Characteristics of Comprehensive Approaches to Cancer Control

- Science, data or evidence-based agenda, priorities and decision-making
- Horizontal planning (functionality)
- Infrastructure support
- Partnerships, broad stakeholder input and shared leadership
- Outcome evaluation
- Planned dissemination/institutionalization



# So where does survivorship fit?



Survivorship broadens the definition of comprehensive cancer control to include activities beyond palliation...



...and prompts a different way of looking at the continuum of cancer control, suggesting a link between survivorship activities and prevention - and a circular rather than linear model for comprehensive approaches to cancer control.



# **Traditional**

**Prevention** Palliation



#### Not-so-traditional

screening dx and treatment

prevention

survivorship

genetic testing

education

palliation

genetic counseling education

impact on family history

prevention lifestyle changes



### CDC addresses Survivorship by...

- Strengthening use of cancer data to explore survivorship issues
- Defining public health objectives related to enhancing the quality of life for people affected by cancer
- Learning from and building partnerships with those for whom survivorship is a personal reality and/or a professional passion
- Assisting grantees and partners to network and share needs, experiences and resources



# CDC and Survivorship





#### State Cancer Registries

- ◆ Patterns of Care Study NPCR is conducting four studies to compare the quality of treatment and stage data reported to 10 NPCR registries with re-abstracted data from the corresponding medical record.
- ◆ Concord Study The Concord Study is an international collaboration between Europe, Canada, and the United States that will measure and explain differences in cancer survival.



# A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies



#### The National Action Plan

Identifies and prioritizes cancer survivorship needs and proposes strategies within four core public health components:

- Surveillance and applied research
- Communication, education, and training
- Programs, policies, and infrastructure
- Access to quality care and services



#### The National Action Plan

Charts a course for how public health can more effectively address cancer survivorship and focus on improving the quality of life for survivors

- Preventing secondary cancers and recurrence
- Promoting appropriate disease management
- Minimizing preventable pain, disability, and psychosocial distress
- Ensuring cancer survivors access to the support and other resources they need



#### National Action Plan Outcomes

- Greater awareness among the general public, policy makers, researchers, advocates, and survivors of the role public health can play in advancing cancer survivorship issues
- Realization among organizations of the need to take action
- ◆ Implementation of recommended strategies to improve the overall experience and quality of life of the millions of Americans who are living with, through, and beyond cancer.



# National Comprehensive Cancer Control Program

"... a way of doing business"

- Support for 57 programs
- Technical assistance for creating and implementing CCC plans
- Evaluation to assess national capacity for and impact of CCC
- CCC Leadership Institutes and other training
- Collaboration with national partners



# Cancer Plans, Spring 2004

- 60 states, tribal entities or territories reviewed
- ◆ 31 with no plan at the time of the review
- 29 with plans and web sites
- 24 current plans reviewed
- 22 with survivorship included



# Top Five Survivorship Issues

- Access to Treatment (22)
- Health Professional Communication, Education and Training (21)
- Consumer Communication, Education and Training (20)
- Access to Clinical Trials (20)
- Palliative Care (18)



## Issues Included in Many Plans

- Quality of Life (17)
- Pain Management (17)
- End of Life Care (16)
- Quality Assurance and Credentialing (16)
- Surveillance (10)



#### Access to Treatment

- Reduce financial barriers to care for cancer patients who are uninsured or underinsured
- Establish and maintain reliable transportation systems in all counties
- Ensure geographic access to state-of-theart treatment services



#### Access to Treatment

Quantify the amount of uncompensated care provided by institutions and physicians and analyze the possible reasons that this care is uncompensated



#### Physician Education

- ♦ Collaborate with health care providers across the state to develop and support regional tumor boards and meetings of multidisciplinary teams to discuss treatment options for challenging cancer cases
  - Explore expansion of existing boards through teleconferencing
  - Identify willing participants
  - Widespread notification of schedule



#### **Consumer Education**

- ♦ By 2002, prostate cancer patients will have their knowledge and understanding of prostate cancer, treatment options, side effects and quality of life issues measured by patient surveys, with findings used to develop patient education activities.
  - Survey newly diagnosed men from diverse areas
  - Design an educational intervention for newly diagnosed patients making treatment decisions



#### Surveillance

- ◆ Continuously collect and maintain data on cancer incidence, stage at diagnosis, treatment, survival, rehabilitation, race/ethnicity, insurance status and mortality, and annually publish rates, trends, and other pertinent studies related to these data;
- Establish plans and implement the training of potential users to appropriately use data sets, particularly non-traditional users.



#### Clinical Trials

- Identify content area experts who are evaluating barriers to diverse populations' participation in clinical trials
- Create a baseline of available clinical trials and their locations
- Identify and document "best practices" used to increase enrollment, especially among diverse populations



#### Surveillance

- ◆ The Department of Health, in collaboration with the cancer control community in the state, must develop additional surveillance capacity in at least 2 areas: the use of clinical trials and the use of palliative care. Produce a comprehensive report.
  - Determine 1) if hospice services were evenly distributed among terminally ill cancer patients in different population subgroups; 2) to what extent full hospice benefits had been used; and 3) where the services had been rendered.



### Quality of Life

- Ensure that appropriate and continuous psychosocial support is provided for every child with cancer and the child's family
  - Through a legislative initiative, require the assignment of a professional caseworker to provide *ongoing* psychosocial assessment and intervention...
  - Partner with the insurance industry to further reimbursement for psychosocial services on an ongoing, outpatient basis.



# Patient Support

Identify and train a Community Care Volunteer Core (CCVC) whose members will act as brokers to support consumers who are seeking prevention or treatment resources



## Pain Management

- ♦ Make the public, patients with cancer and their families aware that pain/symptoms can be controlled and they should expect comfort measures as part of their care
  - Initiate a campaign to provide factual information about cancer pain management
  - Hold Town Hall meetings at regional sites to provide information, distribute literature, answer questions and dispel myths about cancer pain management
  - Add pain management information to the State Cancer website



# Remember that the plans are only a beginning...



#### What's Next?



The Vision must be followed by the Venture. It is not enough to stare up the steps. We must step up the stairs.

V. Havner

